

# VIEWS & REVIEWS

## For patients' sake, don't boycott e-health records

PERSONAL VIEW **Marlene Winfield**

**C**an I be the only patient scratching my head about the BMA's decision to advise general practitioners to boycott the creation of summary care records for their patients? The new record has two main purposes: to provide the NHS with crucial patient information when none is available from other sources, and to give people themselves access to a good summary of their health records whenever they need it.

For me as a patient this means that anyone I ask to help me at evenings and weekends will know basic information about me. This is particularly important now that GPs no longer provide their own out of hours cover for us. Unfortunately, I find that I usually develop a raging urinary tract infection on a Friday night and it would be really helpful for the stranger I ring to know what antibiotics worked for me before, which one caused me to come out in a rash and needs to be avoided lest I am allergic to it, which one made me vomit, and which gave me high fevers and the shakes. After a sleepless night, I can't always remember their names, which aren't very user friendly at the best of times.

I really want to be able to see my own records. Knowing that information passed around about me is correct would

be reassuring. Also, when I am worried, I don't always take in what I've been told if it's complicated. I really would like to be able to review it when I am calmer. But more generally, it's my life and my health and I don't like making important decisions flying blind.

I can appreciate what GPs may be worried about. I would be the first to agree that my health information should remain confidential. But I also expect, as other patients do, that important information about me will be shared with others who need it to give me care. It is well documented that the balance isn't right now, and that patients suffer harm as a result.

It would be very unfortunate if a patient complained about information being shared. All of medicine is a balance of risks, and risk needs to be weighed against the known risks to patients of poor information sharing. GPs worry, too, about information being shared that is not accurate. So do I. What better way to prevent inaccuracy than by giving me access to the information so that I can check it?

Are the risks of the summary care record great enough to justify a wholesale boycott by GPs, acting on my behalf? I find it reassuring that the record is being tried in a few areas first so that problems can be spotted early by an independent evaluation and fixed. If I don't trust having my summary care record on the national database, when I

**I wonder if they ever ask themselves why no major patient group or civil liberties group seems to agree that a boycott is the way to move things on?**

get my letter telling me it will happen in my surgery, I will have four months to tell my GP I don't want one. Or I can say I want one to be created that only I can see. Or I can ask that certain information is not put on it. And I can change my mind at any time. The evaluation will assess how well people were informed of their options.

With all of these safeguards, why are some GPs trying to take this decision out of my hands? I wonder if they ever ask themselves why no major patient group or civil liberties group seems to agree that a boycott is the way to move things on?

In the 1980s, I ran a support group for thousands of British women who had trusted their doctors to fit them with a contraceptive device that turned out to be faulty. At least 3000 got compensation from a \$2.5bn (£1.2bn; €1.8bn) trust fund set up by the US courts. Judging from the many hundreds of letters and phone calls I had, GPs had been slow to act on these women's symptoms—at great cost to their fertility. No one had the information they needed to avoid this tragedy, not least patients.

As Cyril Chantler has observed, treatments are becoming ever more complex and effective, and more dangerous with it. I don't want my doctors taking all the responsibility for my health care and keeping all the information to themselves. I am not alone in this: Angela Coulter's review of research last week (*BMJ* 2007;335:24-7) shows that evidence is mounting: true collaboration produces better outcomes for both patients and the NHS than paternalism. It is precisely why I went to work for NHS Connecting for Health.

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The brilliant legacy  
of John Charnley,  
p 161



## REVIEW OF THE WEEK

# Lethal practice

A new book chronicles insulin's 50 year history as a murder weapon—including stories of doctors engaged in foul play. **Wendy Moore** reports

If one fact emerges with abundant clarity from *Insulin Murders* it is that coauthor Vincent Marks would make the ideal dinner party guest. As a world authority on criminal use of insulin, Marks could spin startling stories of bigamous murderers, serial killers, and bungled miscarriages of justice sufficient to last until well after the last wafer thin mint has been eaten.

Documenting 50 years of legal cases that have implicated insulin as a murder weapon, Marks and his coauthor, medical journalist Caroline Richmond, have produced a compelling account that is at least as thrilling as any best selling crime novel. Beginning in England in 1957 with the first murder proved to have involved insulin, though technically death was caused by drowning, the book details 14 of the most controversial trials in which insulin has played a determining role. In many—including the famous conviction and later acquittal of Claus von Bulow, wrongly accused of murdering his heiress wife by insulin injection, and the case of British nurse Beverly Allitt, convicted of killing four children in her care—Marks testified as an expert witness.

Just as the book provides a galloping account of ingenious attempts by fortune hunting husbands and money grabbing wives to pull off the perfect murder, it also charts the development of the laboratory tests that have often foiled their efforts—and also quite possibly led to wrongful convictions or erroneous acquittals. In this parallel journey, doctors and nurses are as often the villains as the heroes, just as likely to be clinically efficient killers as to be the medical sleuths who unmask them.

Kenneth Barlow, the first proved insulin murderer, convicted of killing his wife by injecting her with insulin then leaving her to drown in a bath, was an unemployed nurse. An astute forensic pathologist cast doubt on Barlow's wife's seemingly natural death, having discovered a tiny puddle of water in the crook of her arm, discrediting Barlow's story that he had tried to resuscitate her. Tests with insulin antibodies on tissue taken from the suspected injection sites not only clinched Barlow's conviction but for the first time destroyed the myth that insulin was the route to the perfect—undetected—murder.

Colin Bouwer, who was found guilty in 2001 of murdering his wife, probably by a succession of prescription drugs including insulin, was a professor of psychiatry at a New Zealand medical school. It was through emails he

had sent to medical experts on hypoglycaemia, purporting to be a forensic psychiatrist investigating a possible insulin death, that his involvement was first suspected.

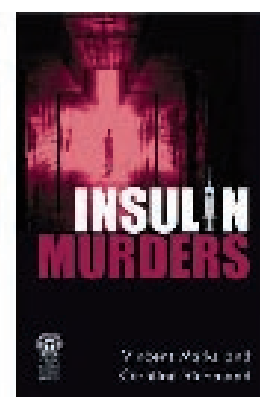
But if *Insulin Murders* is a roller coaster ride to equal any forensic detective television drama, it is also a cautionary tale of medical mishap, misdiagnosis, and misinterpretation. True life, unfortunately, is rarely as straightforward as fiction. Just as the laboratory tests to measure insulin and its criminal misuse have become ever more sophisticated, so evidence of their potential flaws has grown.

Himself a pioneer of the immunoassay test used to measure insulin in blood—first developed in 1960 and still the linchpin of criminal insulin investigations—Marks skilfully recounts the progress and the pitfalls. One difficulty is that tests that are both adequate and vital in diagnosing and treating patients on a hospital ward are not always foolproof in determining cause of death, proving murder, or fingering the possible culprit. Postmortem tests for insulin in brain tissue, which helped convict serial wife killer William Archard, for example, are now discredited. Postmortem urine tests for insulin and C peptide, instrumental in jailing nurse Maria Whiston, are similarly doubted—although both these cases also featured overwhelming circumstantial evidence. But, as conflicting opinions from medical experts in various trials make clear, many results are prone to misinterpretation, inaccuracy, and mix up.

Most fascinating is the case of Deborah Winzar, a nurse convicted in 2000 of murdering her husband by insulin injection, on the basis of a controversial immunoassay test and despite evidence of vomiting—a circumstance unheard of in insulin induced hypoglycaemia. Courageously casting doubt on the test he himself spearheaded, and indeed on the interpretation of his own colleagues who provided the critical result, Marks suggests that Winzar was wrongfully convicted. Tellingly, with the benefit of 50 years' research on insulin measurement, Marks concludes that none of the available tests are sufficiently accurate on their own to provide a safe conviction of murder, unless backed by mass spectrometry.

Since Marks is probably unavailable for dinner party guest turns, his and Richmond's powerful and enlightening book makes a gripping substitute.

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### Insulin Murders: True Life Cases

Vincent Marks, Caroline Richmond

Royal Society of Medicine Press, £12.95, pp 189

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Rating: ★★★★★

**Doctors and nurses are as often the villains as the heroes, just as likely to be clinically efficient killers as sleuths who unmask them**

# Cortina en France

FROM THE  
FRONTLINE  
Des Spence



I remember my family holidays. Lying on top of bags in the back of the Cortina as it careered through France. The wind deafened us because we kept the windows down, through fear of baking. We stopped at exotic service stations, full of the sound of crickets. We heard confused French rock music and smelt Gitanes smoke.

These were solid 24 hour rallies from London to Spain. We had no in-car DVDs, no iPods, no games machines—just the hiss of cassettes. Seven of us were crammed in plus luggage. We played “knuckles,” “slap-pets,” and “paper, scissors, stone.” My father quizzed us on arithmetic, capital cities, and history. In the melting boredom we sang songs or enjoyed the sport of irritating a sibling until they became incandescent with rage. But mostly we just gazed through the window, sweating.

This summer, families will be spared these evocative and collective memories. Nowadays children slip through a largely homogenised and blander Europe. They are pinned down in their booster seats in silent, air conditioned capsules, plugged into a portable world of DVDs, computer games, and 30 gigabytes of music.

Holidays have become yet more poor quality family time. Despite all the sugary emotion we express for

our kids, there is a dissonance as we dump them at kids’ clubs and happily allow them to be glued to small screens the rest of the time. This is a variant of consumerism, anything for more “me time” to lounge and complain by the pool. Little wonder then that children struggle to speak to their parents: the truth is that we no longer seem to want share any real time together.

What is to be done? Ban the high tech social vacuums and boycott the kids’ clubs full of smiling kids’ leaders who wince when you tell them your children are theirs for two weeks. Instead, squabble over cards and board games. Kick a football, and throw a cricket ball. Sing a song or two. Ignore your children’s complaints about being bored. Life is not about being constantly entertained. Gazing through the window on holiday is time to reflect. And it is a catalyst for creativity and the gift that no expensive crammer school can give—imagination.

Share some misery this summer holiday. Perhaps our children might end up with their own collective family memories instead of multimedia shadows. Neil Diamond’s *Cracklin’ Rosie* still makes me smell sweat, rub my knuckles, and smile.

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# Dunno, mate

DRUG TALES AND  
OTHER STORIES  
Ike Iheanacho



Having produced a new treatment, drug companies take great care to avoid testing it too exhaustively in patients. Such an assertion would provoke howls of protest from the drug industry, which would no doubt point out just how much clinical research it does (lots) and contrast this with the amount of non-industry development of new drugs (very little).

While some of this counter-argument is half true, it doesn’t alter the fact that too much essential information about many new drugs is missing when they appear on the market. A simple demonstration of this fact involves subjecting examples of new drugs to two simple questions. Firstly, have they been directly compared with standard comparator treatments in appropriately designed trials? Secondly, does the available research allow confident prediction of the effects (both helpful and harmful) of the drugs in patients from the general population, particularly in the long term? The

answer to both is often “No.”

In response, companies can say, correctly, they only do as they’re told by medicines regulators, the real villains of the piece. The framework that governs licensing of new drugs is ultimately responsible for the low standards that allow companies to conduct studies that duck away from answering key clinical questions. In particular, the overemphasis on inappropriately brief comparisons with placebo (despite the availability of well established alternative drugs or other treatments) is driven as much by the “don’t really care” attitude of regulators as by the commercial wellbeing of the industry.

This unsatisfactory situation is well entrenched and is unlikely to change soon. Ideally, therefore, it should prompt interested scepticism towards new products that have been inadequately tested before launch. Paradoxically, however, some prescribers take the opposite view, dazzled by promotional glamour and somehow reasoning

that the absence of definitive evidence to indicate otherwise is in itself a good enough reason for trying out a new product in preference to tried and trusted older treatments. Such woolly thinking means that a new drug and its owners may enjoy a sort of “dunno dividend”—revenue where use of the treatment is catalysed by lack of knowledge about its real effects.

For truly innovative drugs this factor is relatively small, so robust, ever increasing and enduring is the evidence of net benefit to patients. But for others—noisily hyped but quietly under-researched—the dunno dividend is a crucial (if not dominant) component of the money making potential. And there is certainly no incentive for the companies to generate more complete data that could threaten such a position. Sometimes, for the drug industry, ignorance is bliss.

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# Ordinary people?

America is the land of opportunity, and every one there can reach the maximum of their potential: perhaps that is why so much of its literature is tragic.

There must be failures even—or perhaps especially—in the most open of societies, and failure in such a society is more deeply felt than in a society that itself is a failure.

Raymond Carver is the poet of American failure. His short stories are what he calls “a long line of low rent tragedies.” He was born into a blue collar world; his father, an alcoholic, died young. Carver himself became an alcoholic, until he joined Alcoholics Anonymous, but died aged 50 from lung cancer.

In the world he describes, people have insufficient command of words to express themselves, and love turns to hate. People argue past the point, and never about what is really on their mind. In “One More Thing,” a drunk called L D, who is about to be thrown out of the house by his wife, Maxine, argues with his 15 year old daughter, Rae.

“Tell him, Mom,” Rae said. “Tell him it’s all in his head. Anyone who knows anything about it will tell you that’s where it is.”

“How about sugar diabetes?” L D said. “What about epilepsy? Can the brain control that?” He raised his glass under Maxine’s eyes and finished his drink.

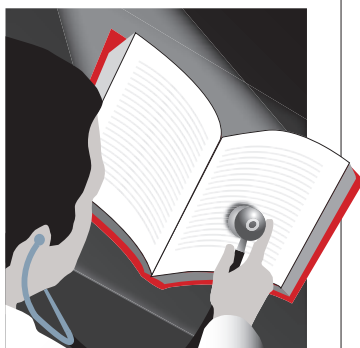
“Diabetes, too,” Rae said. “Epilepsy. Anything! The brain is the most powerful organ in the body, for your information.” She picked up his cigarettes and lit one for herself.

“Cancer. What about cancer?” L D said. He thought he might have her there. He looked at Maxine. “I don’t know how we got started in this,” L D said to Maxine.

“Cancer,” Rae said, and shook her

## BETWEEN THE LINES

Theodore Dalrymple



**What really disturbed me about this story was its suggestion that doctors were just the same as other people: illogical, inconstant, vulnerable**

head at his simplicity. “Cancer, too. Cancer starts in the brain.”

We’ve all heard angry discussions about aetiology like this that are really about something quite different.

In the story “What We Talk About When We Talk About Love,” one of the protagonists is a cardiologist, rather unusually for Carver, whose characters are usually at a much lower occupational level. Indeed, the story begins with the words: “My friend Mel McGinnis was talking. Mel McGinnis is a cardiologist, and sometimes that gives him the right.

“This rather implies that the right to silence in private life is not employed as often as it should be, and that the right to speak is conditional on possession of knowledge or skill of some kind.”

McGinnis and his second wife, Terri, are sitting round a table drinking gin with the narrator and his wife, Laura. A sense of dislocation—emotional, cultural, existential—is deftly conveyed: “We lived in Albuquerque then. But we were all from somewhere else.”

The four of them, progressively drunker, discuss the nature of love. The cardiologist and his second wife hover on the verge of an unpleasant, almost violent, dispute about whether her former lover, Ed—who beat her up, stalked McGinnis and eventually killed himself—really loved her. The subsequent discussion calls into question the reality, even the existence or possibility, of love.

What really disturbed me about this story, however, was not its scepticism about love but its suggestion that doctors were just the same as other people: illogical, inconstant, vulnerable. Surely we are not like others, but are a completely different order of beings?

Theodore Dalrymple is a writer and retired doctor

## MEDICAL CLASSICS

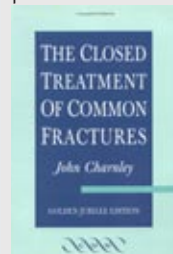
### The Closed Treatment of Common Fractures By Sir John Charnley

First published in 1950

It was five years after the end of the second world war. A young lecturer in orthopaedics from Manchester published a book titled *The Closed Treatment of Common Fractures*—a slim volume with a modest aim: “to re-emphasise the non-operative method.” His target readership was primarily junior trainees in accident and emergency and orthopaedics. His service as a military surgeon in the war almost certainly provided him with ammunition for his work. He had an important message for the hapless doctor left unsupervised to treat common fractures concerning why and how fractures displace and how best to reduce and hold them. His was a unique message, he thought, because after the description of detailed theory, larger textbooks had generally neglected to teach this small matter of practical treatment.

John Charnley (1911–82) was gifted with a superb technical mind. Within a decade he was set to forever transform the practice of hip replacement surgery. With this publication he tried to bring the ill defined art of fracture manipulation into the realms of practical science. He brilliantly explained fracture deformity and the soft tissue hinge by clever use of wooden blocks and leather strips. He was also not shy of borrowing from the industrial heritage of his Mancunian upbringing, using the analogy of gear wheels and crank and connecting rod.

Some of his line drawings might be accused of oversimplification yet are useful to help understand and treat fractures. His no-nonsense style of writing is a pleasure to read. He made his arguments confidently,



deploying occasional bits of evidence based medicine from his own practice. With each common fracture he tried to present a “mental picture” of the deformity to the reader; once the mechanics of displacement were understood the reader could solve the puzzle of reduction. A well reduced fracture will often redisplace in a poorly

applied cast. He then turned the reader’s attention to the proper application of casts. The chapters on treatment of particular fractures are full of practical tips. It is also instructive to see the respect he had for soft tissue preservation—he was, after all, advocating closed treatment mainly to avoid the unhappy consequences of poor handling of soft tissue. His interest in the non-operative treatment of fractured neck of femur and the like may be of historical interest, but more than 50 years, four editions, and three reprints later Charnley’s work is still essential reading for anyone managing fractures.

In many parts of the world today the prohibitive costs of orthopaedic implants mean that non-operative treatment is the only option left to the treating surgeon. However, even in the West, where internal fixation has supplanted non-operative treatment of many of the common fractures that Sir John describes so well, the message is still very pertinent. His interest was in highlighting the “principles,” and in so doing he set a standard that half a century later is still hard to beat.

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